Structures that Support Individualized Funding and Direct Funding by David Wetherow June 1, 2000

...written in hope that these thoughts might make it easier for us to communicate clearly within our own constituency, with the existing service system, with families, advocacy associations, and government.

There is value in being clear about the things that we think *define* Individualized Funding / Direct Funding and the things that can be *supportive* to IF, but don't necessarily define it. If we can agree on the *defining* elements, we are free to develop the *support* elements in many forms and in their own time. The support elements may represent specific projects or initiatives, but they don't *define* IF. This way, we can be clear about the things that are essential for us to ensure, and the things that may be helpful and strategic, but which can be the focus of local experiment, variation, adaptation and change.

Elements that (probably) define IF - 'the bottom line':

- the person or family is at the center of developing a plan, and presenting that plan and a budget proposal to a funder (usually government)
- assistance with planning, creating a proposal, and presenting the proposal that is independent of the funder and independent of potential service providers
- money coming directly into the hands of the person or family, or a personal non-profit entity such as a microboard
- the person or family has *direct control* over day-to-day expenditures
- (ideally) the person or family acts as the *employer-of-record*

Elements that can be *supportive* to IF but don't define IF:

- Structures (organizing forms) that individuals and families might use to help them manage personal resources
- A variety of 'second-level' support services
- The goods and services that individuals and families purchase with the money that they control
- The ways that government and other funders organize themselves
- Underlying and desirable principles, strategies, ideas, examples

Let's look at each of these elements in detail:

Structures (organizing forms) that individuals and families might use to help them manage personal resources, which could include:

- the person or family operating independently
- the person operating with the assistance of their family
- the person or family operating with the assistance of an informal personal network or circle of support
- the person or family operating with the assistance of a personal non-profit entity (e.g. a microboard)
- ... and others

How individuals or families set themselves up to manage IF resources does not define IF. Any of these forms may be useful, and it's helpful if there can be many variations, local experiments, and options to accommodate individual capacities and needs.

Allowing (in fact, welcoming) variation in this area allows for the inclusion of people with a wide

range of needs within a broad IF model. People who wish to be independent in managing their personal resources can do so, and at the same time they can work in solidarity with people who may need, or wish to have, a great deal of assistance in managing their personal resources.

A variety of 'second-level' support services, including:

- assistance with planning
- assistance in creating and presenting proposals to funders
- consultation, information, advice
- training, education, development
- assistance with day-to-day operations (e.g. staffing, payroll, etc.)
- ... and many others

How second-level support services are organized does not define IF. These supports can be provided by individuals, cooperatives, non-profits, incorporated businesses, etc. Any of these forms may be useful, and it is helpful if there can be many variations, local experiments, and options to accommodate individual capacities and needs and community capacities and needs.

Some of the ways we've seen second-level support services organized include 'brokerage' projects, independent practitioners, microboard associations, etc.

We struggle a bit with the awkwardness of the term 'second-level supports', but have not as yet found a more descriptive term that does not limit consideration of this important set of supports to one specific form. One parent described what she was looking for as a 'personal agent'; this comes closer, but may still be too specific.

Following the principles of IF, it would be desirable for individuals and families to have *direct access* to the funds that would allow them to select and purchase second-level support services - absolutely in the operational stage, but also in the planning and development stage. It's one more way of ensuring that independent planning is truly independent.

The goods and services that individuals and families purchase with the money that they control, including:

- housing, transportation, adaptive equipment, etc.
- education, training
- personal care assistants, staff
- professional services (such as PT, OT, speech, etc.)
- ... and many others

How people organize to provide these goods and services does not define IF. These things can be provided by individuals, cooperatives, non-profits, generic community services, incorporated businesses, etc. Any of these forms may be useful, and it's helpful if there can be many variations, local experiments, and options to accommodate individual capacities and needs and community capacities and needs.

Structures adopted by government and other funders, who may create or require:

- mediating structures
- fiscal intermediaries
- accountability and evaluation structures
- ... and many other elements

How government organizes to support individuals and families with direct funding, and meet the requirements of good stewardship and public accountability, does not define IF. Government may deliver support through its own administrative structures, quasi-governmental corporations, area agencies, non-profits, etc. Any of these forms may be useful, and it's probably helpful if there can be variations, local experiments, and options to accommodate local community capacities and needs. It is critical that any and all of these structures be as free as possible of conflict of interest and inherent role conflicts.

Underlying and desirable principles, strategies, ideas, examples, alliances, affiliations, etc.

All of these things are desirable and useful, but they do not define IF. There are many things that we all hope for as we pursue this path: greater involvement on the part of the broader community, powerful examples, a commitment to learning and sharing ideas, democratic structures, services and supports that are strategic and powerful and adaptive, a spirit of inclusion, and many others.

A possible set of implementation structures and a development strategy:

If we can agree on what constitutes the defining 'core' characteristics of IF, and what may be helpful (but not defining) supports and structures, we can explore a variety of development and implementation strategies that might support a successful IF initiative in a given jurisdiction. If there is something about this that we discover isn't working, it can be changed or discarded. If someone thinks of something that can be incorporated that will make it better, it can be incorporated.

Here are the structures, as best as we can describe them:

The person (or family) who is the potential recipient of direct funds

This person may be operating independently, or may be supported by friends, family members, other helpful allies, or a personal non-profit.

Sources for assistance with planning, independent of government and potential service providers

It is desirable if the individual or family has direct access to the funds that would allow them to select and purchase their assistance in planning and preparing a proposal to funders

Someone who can receive the proposal, and who has the power to say 'yes'

In order for the person receiving the proposal to have the power to say 'yes', s/he must be attached to a body that actually has the money for IF.

It would definitely be helpful if this person were not conflicted about IF 'versus' other approaches to funding.

A body that actually has the money for IF

We think it would help if the second-largest body (the body that has the resources and mandate to deliver IF) were closer to the community and were separate from the largest body - the one that contains all the resources and is the most likely to carry elements of the 'old culture' for some time.

It would definitely be helpful if:

this body were not conflicted about IF 'versus' other approaches to funding.